

HPSC 2001 Policy Issues in the Life Sciences

Course Syllabus

2012-13 session | Convenor : Dr Brian Balmer | b.balmer@ucl.ac.uk
Postgraduate Teaching Assistant : Ms Melanie Smallman | m.smallman@ucl.ac.uk

About this course

The purpose of this course is to provide students with a critical overview of policy issues arising from developments in the biological sciences. The course will cover a variety of issues which will include: medical research policy, the BSE crisis, debates about the social acceptability of recombinant DNA research (GM crops, genetic testing, DNA profiling), controlling biological weapons research, synthetic biology, human and animal experimentation. The course will also introduce students to some of the theories dealing with the complex relationship between science and society.

By the end of this course you should:

- Be able to analyse the social and political dimensions of debates in the life sciences
- Be able to evaluate the consequences of developments in life sciences
- Have detailed knowledge of a number of case studies of policy issues in the life sciences
- Be able to criticize simplistic and popular notions of the relationship between science, technology and society.

Course Information

Basic course information

Course website:	On Moodle
Moodle Web site:	Search 'HPSC2001'
Assessment:	This term's course will be assessed on the basis of <i>three</i> written assignments: two essays (one short, one long) and a book review. The three pieces carry equal weight.
Timetable:	www.ucl.ac.uk/sts/hpsc
Prerequisites:	no pre-requisites, course designed for year 2 and above undergraduate students
Required texts:	See reading list
Course tutor:	Dr Brian Balmer

Contact:	b.balmer@ucl.ac.uk t: 020 7679 3924
Web:	www.ucl.ac.uk/silva/sts/staff/balmer
Office location:	22 Gordon Square, Room 2.2
Office hours:	Monday 12-1pm Thursday 11-12am

Schedule

UCL Week	Topic	Date	Activity
20	Introduction: Science & Social Change	1 Oct	Consult Moodle before class
21	"A conflict of interest?": Biomedical Research Policy and University-Industry Links	8 Oct	Consult Moodle before class
22	Genetic Screening and Testing	15 Oct	Consult Moodle before class
23	DNA Profiling and Crime	22 Oct	Consult Moodle before class
24	GM Crops and Science Policy	29 Oct	Consult Moodle before class
24	Assignment 1 deadline	2 Nov	
25	Reading Week	5-9 Nov	
26	"Mad Cow Disease": BSE, CJD and Science Advice	12 Nov	Consult Moodle before class
27	"Building Life?": Synthetic Biology	19 Nov	Consult Moodle before class
28	Controlling Biological Weapons	26 Nov	Consult Moodle before class
28	Assignment 2 deadline	28 Nov	
29	Human Experimentation	3 Dec	Consult Moodle before class Consult Moodle
30	Animal Experimentation	10 Dec	Consult Moodle before class
	Assignment 3 deadline	7 Jan 2013	

Assessments

Summary

	Description	Deadline	Word limit
1	Short essay	11.59 pm Fri 2 Nov	1,500
2	Review article	11.59pm Wed 28 Nov	900
3	Long Essay	11.59pm Mon 7 Jan	2,500

Full details and instructions are at the end of this document.

Assignments

This term's course will be assessed on the basis of *three* written assignments: two essays (one short, one long) and a book review. The three pieces carry equal weight. A list of suggested essay questions is included with this reading list. If you wish to write an essay connected with the course but not on the list you should see me to discuss a title. Students may discuss any aspects of their essays with me during my office hours. There is no exam for this course but you are expected to show evidence of wide reading and critical thought in your essays.

Full details and instructions are at the end of this document

Essays must be submitted via Moodle

In order to be deemed 'complete' on this module students must attempt one assignment.

Criteria for assessment

The departmental marking guidelines for individual items of assessment can be found in the STS Student Handbook.

Aims & objectives

The purpose of this course is to provide students with a critical overview of policy issues arising from developments in the biological sciences. The course will cover a variety of issues which will include: medical research policy, the BSE crisis, debates about the social acceptability of recombinant DNA research (GM crops, genetic testing, DNA profiling), controlling biological weapons research, nanotechnology, human and animal experimentation. The course will also introduce students to some of the theories dealing with the complex relationship between science and society.

By the end of this course you should:

- Be able to analyse the social and political dimensions of debates in the life sciences
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Course expectations

There will be one lecture each week on Mondays 10 - 11am, in Torrington 1-19, Galton LT, and one seminar each week on Monday afternoon (1-2pm, 2-3pm; 4-5pm see UCL timetable for rooms). The seminars are **not** optional.

There will be a reading week, with no lectures or seminars, November 7th-11th.

A poor seminar attendance record, usually 3 undocumented absences, may result in a mark of zero for any further essays submitted during the course. Continued absence will result in an 'incomplete' mark which is equivalent to a fail.

Please note that electronic recording of lectures is not permitted without permission from the course tutor.

Reading for this course

The notes that you take in lectures will not be detailed enough to understand a topic or to write an essay on that topic. It is therefore essential that you make use of the reading list. You are *not* expected to read all of the material. You will be expected to read at least one piece each week in preparation for seminars and you will certainly need to read widely for your essays and may include material from beyond the reading list. However, read critically: you don't have to agree or disagree with everything you read – but you should be able to say why you hold your views.

Where to find the reading material

There is no one text which covers this course. Most of the reading material is kept in the DMS Watson library, material marked [TC *nnnn*] is in the teaching collection so usually available electronically or from the issue desk. The number, *nnnn*, is the teaching collection reference number. Some material is in the library and *also* in the teaching collection. Senate House Library holds some of the material. *The library takes an increasing number of journals on-line, so make sure you check whether articles are available on-line.*

A small number of marked readings marked [D] have been digitized by the Library and can be obtained by clicking Online Resources then Reading Lists on line and searching for the course code. Or go to <http://ls-tlss.ucl.ac.uk/> [remember to click on 'previous years lists']

You are also encouraged to use the Wellcome Library (183 Euston Road). This a reference library with a large collection of science policy material - including much of the material relevant to the course.

You are also encouraged to use the internet for research. However make sure you reference the full web address, the site title and date visited. Be critical of what you read and be careful of purely descriptive sites such as Wikipedia – I will be looking for evidence of some hard thinking and argument in your essays, not simple regurgitation of basic information. Also note that plagiarism, particularly involving internet sources, will be treated as a severe exam irregularity.

Important policy information

Below are listed some important points of policy. Further details of all these policies can be found in the STS Student Handbook www.ucl.ac.uk/sts/handbook

Late submission of coursework

Penalties for late coursework submission are as follows:

- loss of 5 marks for work submitted less than 24 hours late
- loss of 15 marks for work submitted between 1 and 7 days late
- loss of all marks (i.e. work is graded 0) if submitted more than 7 days late

These rules are statutory and non-negotiable.

Coursework word limits

Penalties for over-length coursework are as follows:

- Assessed work should not be more than 10% longer than the prescribed word count. Assessed work with a stated word count above this maximum cannot be accepted for submission, but will be immediately returned to the student with instructions to reduce the word length. The work may then be resubmitted, except insofar as penalties for late submission may apply.
- If submitted work is subsequently found to have an inaccurately stated word count, and to exceed the upper word limit by at least 10% and by less than 20%, the mark will be reduced by ten percentage marks, subject to a minimum mark of a minimum pass assuming that the work merited a pass.
- For work which exceeds the upper word limit by 20% or more, a mark of zero will be recorded.
- Footnotes and endnotes **do** count as part of the word limit
- Bibliography, tables, pictures and graphs **do not** count as part of the word limit.

Extensions

If unforeseeable circumstances prevent the completion of a piece of coursework, students may request an extension to the set deadline. Please consult the STS Student Handbook for further guidance on acceptable grounds for requesting an extension. Extensions must be negotiated in advance with the course tutor. Students to whom STS is parent department may also request an extension from their Personal Tutor. No extension is considered official without written approval.

The request for extension form can be found at: www.ucl.ac.uk/sts/study

Plagiarism

The *UCL Student Handbook* defines plagiarism as “the presentation of another person’s thoughts or words or artefacts or software as though they were [your] own”. Students are expected to know the College and Department policies in detail and to avoid even the appearance of inappropriate behaviour. In the first demonstrated instance of plagiarism or other irregularities in this course, students normally will receive a 0 F for the course and will be referred to the department and College officials for further action. All course work is subject to scrutiny against past papers and other materials for irregularities. Electronic and other checks will be conducted; see the *STS student handbook* for additional information.

Attendance

Regular attendance is mandatory.

Requirements to complete modules

Students are required to be ‘complete’ in all modules. Normally all assignments must be attempted in order for students to be considered complete. This is different from ‘passing’ a module which requires a minimum overall module mark of 40%.

Assessment and additional examiners

Assessed materials are marked by the course tutors. These provisional marks will be distributed to students at the first opportunity. To ensure fairness, materials subsequently are scrutinised by a second examiner within the Department, and a consensus is reached on these

separate assessments. All assessed materials and the consensus marks are made available for scrutiny by an examiner external to UCL. Marks are considered final only after the Board of Examiners for Science and Technology Studies has approved them in their annual meeting near the close of Term three.

Disputed marks

Students must endeavour to discuss any grievances over marks informally with the course tutor in the first instance. If informal discussion fails to resolve the matter satisfactorily and there appears to be genuine and substantive grounds for appeal, the student should submit a written explanation of their grievance to the chair of the board of examiners. A final formal written appeal can be made to the College Registrar.

Mechanisms for student feedback

Students have a variety of means for commenting on the module and module tutor. These include written module evaluations at the end of term, regular lecture assessments offered by the module tutor, and in-session opportunities. Students are welcome to bring comments and criticisms to the module tutor in the first instance, by anonymous note if necessary, then to their personal tutor or the STS undergraduate tutor. The department schedules regular meetings of the Undergraduate Student Staff Consultative Committee to which all students are invited.

Topic 1: Science and Social Change

In order to engage seriously with debates concerning science, technology and society it is important to think beyond oversimplified models of the science-society relationship. This session will introduce you to some of the critical thinking that has taken place on this subject.

Essential Reading:

Stilgoe, J et al (2006), *The Received Wisdom: Opening Up Expert Advice* (London: Demos).

Chapter 1 'Speaking truth to power' ... but if you are enjoying it keep reading... Demos is a think-tank, so think rather than take copious notes... which bits do you agree/disagree with? [Available at <http://www.demos.co.uk/publications/receivedwisdom>]

Additional Reading

Bridgstock, M et al (1999), *Science, Technology, and Society : an Introduction* (Cambridge: CUP) Chapter 5 'Controversies Regarding Science and Technology'

[Available on-line from library: click Online <http://ls-tlss.ucl.ac.uk/> and search for this course, tick the 'previous year' box to make sure]

Topic 2: Research Policy and the Life Sciences

This topic explores how the landscape of academic research has changed over the past quarter century or so. Given that we cannot spend an infinite amount of money on biomedical research, we have to decide what to fund and what not to fund. 'We' in this context used to mean only scientists – after all, they do the science – but has increasingly included Government, industry and 'consumers'.

Essential Reading:

Johnston, J (2008), 'Conflict of Interest in Biomedical Research' in *From Birth to Death and Bench to Clinic: The Hastings Center Bioethics Briefing Book*
<http://www.thehastingscenter.org/Publications/BriefingBook/>

Angell, M (2008), 'Industry-Sponsored Research: A Broken System', *JAMA* 200(9):1069-71

Additional Reading:

Theories:

EITHER

Hessels, LK and van Lente, H (2008), 'Re-thinking new knowledge production: A literature review and a research agenda', *Research Policy* 37(4):740-760

[Summarises some of the key criticisms of the Mode 1/2 thesis]

Frickel, S et al (2010), 'Undone Science: Charting Social Movement and Civil Society Challenges to Research Agenda Setting', *Science, Technology and Human Values* 35(4):444-473.

Mirowski, P and Sent E (2008), 'The Commercialization of Science and the Response of STS' in Hackett, EJ *et al* (eds) *The Handbook of Science and Technology Studies*, Third Edition (Cambridge: MIT Press).

Royal Society (2010), *The Scientific Century: Securing Our Future Prosperity* (London: Royal Society) <http://royalsociety.org/policy/publications/2010/scientific-century/>
[A recent report that is worth skimming through to see how the global landscape of science has changed in the early 21st century]

Government funding:

Salter, B and Salter, C (2010), 'Governing Innovation in the Biomedicine Economy: Stem Cell Science in the USA', *Science and Public Policy* 32(2):87-100 (Sets out a framework for understanding innovation – a bit of social science jargon in the early parts which may be a bit daunting, but you should be able to get them main messages).

Lakoff, A (2010), 'Two Regimes of Global Health', *Humanity Journal* 1(1) on-line at <http://www.humanityjournal.org/humanity-volume-1-issue-1>
[Thoughtful discussion of a case study about avian flu research and how global issues shape what research gets done]

Nightingale, P and Scott, A (2007), 'Peer Review and the Relevance Gap: Ten Suggestions for Policy Makers', *Science and Public Policy* 34(8) 543-533.

Morris, N and Rip, A (2006), 'Scientists' coping strategies in an evolving research system: the case of life scientists in the UK', *Science and Public Policy*, Volume 33, Number 4, 1 May 2006, pp. 253-263.

Hessels, LK *et al* (2009), 'In search of relevance: the changing contract between science and society', *Science and Public Policy* 36(5):387-401

Industry-Academia:

Sergio Sismondo (2009) 'Ghosts in the Machine: Publication Planning in the Medical Sciences', *Social Studies of Science*, Apr 2009; vol. 39: pp. 171 - 198.[A study of ghost writing]

Nelkin, D and Andrews, L (1998), 'Homo economicus: commercialisation of body tissue in the age of biotechnology', *Hastings Center Report* Vol.28 pp.30-39.
On-line at: <http://ls-tlss.ucl.ac.uk/cgi-bin/displaylist?module=10HPSC2001>

Weatherall, D (2000), 'Academia and Industry: Increasingly Uneasy Bedfellows', *The Lancet*, Vol. 355 (9215) 1574 (5 May 2000)

Oliveri, NF (2003), 'Patient's Health or Company Profits? The Commercialisation of Academic Research', *Science and Engineering Ethics* Vol.9 No.1 pp.29-41. (Wellcome library)

Weatherall, D (2003), 'Problems for Biomedical Research at the Academia-Industry Interface', *Science and Engineering Ethics* Vol.9 No.1 pp43-48 (Wellcome library).

Nathan, DG and Weatherall D (1999), 'Academia and Industry: Lessons from Unfortunate Events in Toronto', *The Lancet* 353 (9155) 771-772 (6 March).

Topic 3 Genetic Testing and Screening

The Human Genome Project was a global attempt to locate all of the genes in the human genetic complement. Commentators are now talking about a postgenomic age. The social and ethical implications for health care, insurance and employment have been widely discussed with benefits for health but also possible discrimination in a 'genetic supermarket'.

Essential Reading:

Press, N. (2008) 'Genetic Testing and Screening' Chapter 16 in *From Birth to Death and Bench to Clinic: The Hastings Center Bioethics Briefing Book*
<http://www.thehastingscenter.org/Publications/BriefingBook/>

Additional Reading

Also the journal *New Genetics and Society* publishes up-to-date research on this topic.

Clayton, WE (2003), 'Ethical, Legal and Social Implications of Genomic Medicine', *New England Journal of Medicine*, 349: 562-569 (Short, accessible overview of some of the key issues)

Saukko, P. *et al* (2006) 'Are genetic tests exceptional? Lessons from a qualitative study on thrombophilia'. *Social Science and Medicine* 63 (7): 1947-1959.

Compare with:

Lock, M (2011), 'Dementia Entanglements in a Postgenomic Era', *Science, Technology and Human Values* 36(5): 685-703

Hennen, L *et al* (2010), 'Direct to Consumer Genetic Testing: Insights from an Internet Scan', *New Genetics and Society* 29(2):167-186.

Murray, T (1997), 'Genetic Exceptionalism and 'Future Diaries': Is Genetic Information Different from Other Medical Information?' in *Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era* by Rothstein, M (editor) (Yale University Press) [Also in TC SCIENCE 4918]

Hallowell, N *et al* (2003), 'Balancing Autonomy and Responsibility: The Ethics of Generating and Disclosing Genetic Information', *Journal of Medical Ethics* 29:74-83.

Pilnick, A (2002), *Genetics and Society* (OUP), Chapter 5.

(If you are a bit unsure about how much genetics you know, take a look at the earlier chapters too)

Human Genetics Commission (2006), *Choosing the Future: Genetics and Reproductive Decision-Making* (Report covers a wider range of issues than testing – but gives a good feel for the fairly recent UK situation) (See note below on the HGC:
<http://www.hgc.gov.uk/UploadDocs/DocPub/Document/ChooseFuturefull.pdf>

Novas, C and Rose, N (2000), 'Genetic Risk and the Birth of the Somatic Individual', *Economy and Society* 29(4) pp485-513 (Argues that genetic tests do not encourage fatalism but do encourage new types of responsibility)

Mitra, J (2006), 'Genetic exceptionalism' and precautionary politics: regulating for uncertainty in Britain's genetics and insurance policy process', *Science and Public Policy* 33(8): 585-600.

Draper E (1992), 'Genetic Testing in the Workplace', in Nelkin D (1992), *Controversy: The Politics of Technical Decisions* (3rd Edition) (Newbury Park: Sage). pp147-176 (Still some of the only research to be carried out on testing in the workplace).

Web-Site

Human Genetics Commission: <http://www.hgc.gov.uk/>

The HGC closed this year (2012) and produced many advisory reports on social aspects of genetics. The website was still there on 10 Sep 2012 and may be worth looking at – the HGC reports and other material are being archived at the National Archives and British Library.

(Don't go to www.hgc.org.uk by accident)

Topic 4. DNA Profiling (Fingerprinting)

DNA fingerprinting can be regarded as a new and powerful tool for forensic science. Alternatively, with the possibility of a national DNA fingerprint database, the technology could be regarded as an infringement of civil liberties. This session will cover the debate over the virtues and dangers of the technique.

Essential Reading:

EITHER:

Nuffield Council on Bioethics (2007), *The Forensic Use of Bioinformation: Ethical Issues* (Comprehensive so read selectively, especially look at Ch 3 which deals briefly with the 'if you've nothing to hide, you've nothing to fear' arguments or the Short Guide for a quick overview of the issues):

http://www.nuffieldbioethics.org/go/ourwork/bioinformationuse/publication_441.html

Additional Reading:

Maschke, K (2008) 'DNA and Law Enforcement' in *From Birth to Death and Bench to Clinic: The Hastings Center Bioethics Briefing Book*

<http://www.thehastingscenter.org/Publications/BriefingBook/>

Nelkin, D and Andrews, L (1999), 'DNA Identification and Surveillance Creep' in Conrad, P and Gabe, R (eds) *Sociological Perspectives on the New Genetics* (Oxford: Blackwell)

Wallace, H (2006), 'The UK National Database: Balancing Crime Detection, Human Rights and Privacy', *EMBO Reports*, Vol 7 (Special Issue) pp26-30

Simon A. Cole, Michael Lynch (2006) 'The Social and Legal Construction of Suspects' *Annual Review of Law and Social Science*, Vol. 2: 39-60 (Thought-provoking discussion of DNA databases)

Heinemann, T et al (2012), 'Risky Profiles: Societal Dimensions of Forensic Uses of DNA Profiling Technology', *New Genetics and Society* 31(3): 249-258 (This is an introduction to a special edition of this journal, with all the articles dealing with DNA profiling – read this intro to see whether the other articles are going to be helpful)

Williams, R and Johnson, P (2005), 'Inclusiveness, Effectiveness and Intrusiveness: Issues in the Developing Uses of DNA Profiling in Support of Criminal Investigations', *Journal of Law, Medicine and Ethics* 33:454-558.

Lynch, M and McNally, R (2003), ' "Science", "common sense", and DNA evidence: a legal controversy about the public understanding of science', *Public Understanding of Science*, 12(1): 83-104. (Detailed case study that challenges the distinction between 'common sense' and 'scientific' evidence)

Linacre, A (2003) 'The UK National DNA Database', *Lancet* 361:1841-42
AND

Pascali, VL *et al* (2003), 'The Dark Side of the UK National DNA Database', *Lancet* 362:834

Kitcher, P (1996), *The Lives to Come* (Penguin) (Chapter 7)

Cho, M and Sankar, P (2004) 'Forensic genetics and ethical, legal and social implications beyond the clinic', *Nature Genetics* 36:S8-S12

Useful web-site, Human Genetics Commission: <http://www.hgc.gov.uk> [Includes links to the House of Commons Select Committee on Science & Technology report on genetic databases and to the relevant sections of the Criminal Justice and Police Act 2001]. HGC has closed but website was still online though inactive on 10 Sept 2012.

Topic 5. Release of GMOs into the Environment

Biotechnology presents modern societies with immense opportunities - but also immense challenges. A key problem is whether or not the deliberate release of genetically modified organisms (GMOs) into the environment is safe – both for human health and the environment. In an area of contested claims and where the evidence is not clear-cut, this topic raises more fundamental issues about the role of science and expertise in the regulation of technology.

Essential Reading

Two sharply contrasting views of the GM Debate – read **both**:

Burke, D (2004), ‘GM Food and Crops: What went wrong in the UK?’, *EMBO Reports* [European Molecular Biology Organisation], Vol 5(5): 432-436

Grove-White, R (2006), ‘Britain’s Genetically Modified Crop Controversies: The Agriculture and Environment Commission and the Negotiation of ‘Uncertainty’’, *Community Genetics* Vol.9: 170-177

Also

If Grove-White’s ideas about precaution and uncertainty seem a bit vague read:

Stirling, A (2007), ‘Risk, Precaution and Science: Towards a More Constructive Debate’, *EMBO Reports* 8(4):309-315

Additional Reading:

Jasanoff, S (1995), “Product, Process, or Programme: Three Cultures and the Regulation of Biotechnology”, in M. Bauer (ed) *Resistance to New Technology: Nuclear Power, Information Technology and Biotechnology* (Cambridge: Cambridge University Press) pp311-331 (An older article but shows how different regulatory frameworks can treat the same technology differently, particularly depending on how they think about the role of science in informing the debate). [Available on-line from library: click Online <http://ls-tlss.ucl.ac.uk/> and search for this course]

Mayer, S and Stirling, A (2004), ‘GM crops, for good or bad? Those who choose the questions, determine the answers’, *European Molecular Biology Organisation Reports*, 5 (11): 1021-24 (On-line under *EMBO Reports* or from Genewatch website).

Gaskell, G (2004), ‘Science policy and society: the British debate over GM agriculture’, *Current Opinion in Biotechnology* 15(3): 241-45.

Bonneuil, C *et al* (2008), ‘Disentrenching Experiment: The Construction of GM Crop Field Trials as a Social Problem’, *Science, Technology & Human Values* 33:201-229 (Uses quite a bit of STS theory, non-STS students persist though, shows how the debate was not just about one thing, but was ‘framed’ differently over time)

Levidow, L and Boschert, K (2011), ‘Segregating GM Crops: Why a Contentious “risk” issue in Europe?’, *Science as Culture* 20(2):255-279. (Also uses ‘framing’ to try to understand the debate about GM products accidentally mixing with non-GM)

Freeman, J *et al* (2011), ‘Agricultural biotechnology and regulatory innovation in India’, *Science and Public Policy* 38(4): 319-331. (This gives a good perspective on the GM debate in a non-western country).

Jasanoff, S (2005), ‘In the Democracies of DNA: Ontological Uncertainty and Political Order in Three States’, *New Genetics and Society* 24(2):139-156. (Compares GM crops with other

biotech issues in three different countries to argue that there are patterns in national responses)

Bowring, F (2003), *Science, Seeds and Cyborgs: Biotechnology and the Appropriation of Life* (Verso) Chapter 2 (A particularly critical argument).

Compare with

Batista, R and Oliviera, M (2009), 'Facts and Fiction of Genetically Engineered Food', *Trends in Biotechnology* 27(5):277-286 (A particularly supportive argument).

Topic 6: BSE, CJD and Science Advice

The BSE saga that took place in the UK from 1986 onwards is one of the most dramatic public health crises of the 20th century. Over three million cattle have now been slaughtered and the overall cost of the crisis now exceeds four billion pounds. For years, the Government and its scientific advisers kept repeating that "British Beef is safe". Yet, in March 1996 they announced that BSE had spread to humans. How can we explain this spectacular shift.

Essential Reading

Two very different views of the BSE affair, read both:

Millstone, E and van Zwanenberg, P (2003) 'BSE: A Paradigm of Policy Failure' in *The Political Quarterly* Vol.74 No1. pp27-37

Forbes, I (2004), 'Making a Crisis out of a Drama: The Political Analysis of BSE Policy-Making in the UK', *Political Studies* 52: 342-357

Additional Reading

Basic information on BSE: <http://www.who.int/mediacentre/factsheets/fs113/en/>

Millstone, E and van Zwanenberg, P (2001), 'Politics of Expert Advice: Lessons from the Early History of the BSE Saga', *Science and Public Policy*, Vol 28 (April) No.2 (More detailed empirical analysis which shows how 'scientific' decisions were framed by wider social, economic and political considerations) [TC 5105]

Stilgoe, J et al (2006), *The Received Wisdom: Opening Up Expert Advice* (London: Demos). Chapter 2 'The new shape of expert advice'.
[Available at <http://www.demos.co.uk/publications/receivedwisdom>]

Beck, M et al (2005), 'Public Administration, Science, and Risk Assessment: A Case Study of the U.K. Bovine Spongiform Encephalopathy Crisis' *Public Administration Review* Volume 65 Issue 4, Pages 396 – 408 [Besides analysis, this has a useful chronology and overview of key committees]

Millstone, E (2009), 'Science, risk and governance: Radical rhetorics and the realities of reform in food safety governance' *Research Policy* Volume 38, Issue 4, May 2009, Pages 624-636 [Sets BSE and its legacy in a wider context]

Millstone, E and van Zwanenberg, P (2005), *BSE: Risk, Science and Governance* (Oxford: OUP).

Frewer, L and Salter, B (2002), 'Public attitudes, scientific advice and the politics of regulatory policy: the case of BSE', *Science and Public Policy*, 29(2), p137- 45

Jasanoff, S (1997), 'Civilization and Madness: The Great BSE Scare of 1996', *Public Understanding of Science* Vo.6 pp.221-232

Miller, D (1999) 'Risk, science and policy: definitional struggles, information management, the media and BSE', *Social Science and Medicine* 49(9), pp.1239-1255

Goethals, C *et al* (1998), 'The Politics of BSE: Negotiating the Public's Health', in Ratzan, Scott C (ed) *The Mad Cow Crisis: Health and the Public Good* (London: UCL Press) [[Available on-line from library: click Online Resources then Reading Lists and search for this course]

Winter, M (1996), 'Intersecting Departmental Responsibilities, Administrative Confusion and the role of science in Government: The Case of BSE', *Parliamentary Affairs* Vol.49 No.4 pp.550-565.

Wilson, Chris (2004), 'Intersecting Discourses: MMR vaccine and BSE', *Science as Culture* 13(1): 75-88.

Topic 7. "Building Life": Synthetic Biology

"Synthetic biology helps solve biological engineering problems by adapting engineering concepts to design and reconstruct new biological parts, or redesign existing, natural biological systems" (Garfinkel et al 2008). Actually, the term "synthetic biology" is a rather loose term that covers a range of research from creating custom "parts" of organisms (such as genes), building organisms with minimal genomes, through to building whole organisms (such as viruses) from scratch. It is claimed that this brings an "engineering" approach into biology and this raises a range of questions about ownership (intellectual property), the natural and artificial, safety and security etc. On the other hand, there are counter-claims that these are not particularly novel issues.

Essential Reading:

Garfinkel, M et al (2008) 'Synthetic Biology' in *From Birth to Death and Bench to Clinic: The Hastings Center Bioethics Briefing Book*
<http://www.thehastingscenter.org/Publications/BriefingBook/>

Additional Reading:

O'Malley, M, Powell, A, Davies, J and Calvert, J (2008) Knowledge-making distinctions in synthetic biology *BioEssays* Vol. 30, No.1, pp.57–65.

- Yearley, S (2009), 'The Ethical Landscape: Identifying the Right Way to think about the ethical and societal aspects of synthetic biology research and products', *Journal of the Royal Society Interface* 6 S559-S564.
- Henkel J. and Maurer, S.M. (2009) Parts, property and sharing. *Nature Biotechnology*, 27, 12, 1095-1098.
- Nuffield Council on Bioethics (2002) *The Ethics of Patenting DNA*. London: Nuffield Council on Bioethics, Chapters 2 & 3. Online at <http://www.nuffieldbioethics.org/sites/default/files/The%20ethics%20of%20patenting%20DNA%20a%20discussion%20paper.pdf>
- Tait, J (2009) Upstream Engagement and the Governance of Science: the shadow of the GM crops experience in Europe. *EMBO reports* 10(S1): S18-S22.
- Jonathan B. Tucker and Raymond A. Zilinskas, "The Promise and Perils of Synthetic Biology," *New Atlantis*, Spring 2006.
- Cho, M and Reiman, D (2010), 'Synthetic "Life", Ethics, National Security, and Public Discourse, *Science* 329 pp38-39.
- Stracey, F. (2009) Bio-art: the ethics behind the aesthetics. *Nat Rev Mol Cell Biol* 10, 496-500.
- Alper, J (2009), 'Biotech in the Basement', *Nature Biotechnology* 27(12) Dec. pp1077-78.
- Calvert, J (2008), 'The Commodification of Emergence: Systems Biology, Synthetic Biology and Intellectual Property', *BioSocieties* 3: 383-398.

Topic 8. Biological Weapons Control

In 1991 it was *estimated* that a 20kt nuclear warhead could kill 40,000 people and injure another 40,000; a chemical warhead of 300kg Sarin (nerve gas) could under the same conditions kill 200-3,000 people; a 30kg anthrax bomb would probably kill between 20,000 - 80,000 people. Biological weapons are relatively easy and cheap to make and it is believed that between 8 and 10 countries currently have undeclared biological weapons programmes. This session looks at the nature of biological warfare and possible methods for controlling biological weapons.

Essential Reading:

Kelle, A et al (2006), 'Science, Technology and the BW Prohibition Regime' in Kelle, A *et al*, *Controlling Biochemical Weapons: Adapting Multilateral Arms Control for the 21st Century* (Palgrave) [Available on-line from library: click Online Resources then Reading Lists and search for this course]

Additional Reading:

Kelle, A M. Dando and K. Nixdorff (2010) Strengthening BWC Prevention of State-sponsored Bioweapons, in *Bulletin of the Atomic Scientists*, Vol.66, No.1, pp.18-23

McLeish, C and Nightingale, P (2007), 'Biosecurity, Bioterrorism and the Increasing Convergence of Science and Security Policy', *Research Policy* Vol.36 No.10 pp.1635-1654

Littlewood, J (2008), 'Managing Biological Disarmament: The UK Experience', *Science and Public Policy* 35(1): 13-20. [Senate House library, you can get this electronically if you have a Senate House library card]

Tucker, J (2012), *Innovation, Dual-Use and Security: Managing the Risks of Emerging Biological and Chemical Technologies* (Cambridge MA: MIT Press) (Chapters 1 and 2).(E-book ordered for the library).

Guillemin, J (2005), *Biological Weapons: From State-Sponsored Programs to Contemporary Bioterrorism* (Columbia) (Chapters 1, 8 and 9)

John Rubin Productions (2007) 'The Living Weapon' (Emmy award winning documentary) <http://www.pbs.org/wgbh/amex/weapon/filmmore/index.html>

Foreign and Commonwealth Office (2002) *Strengthening the Biological and Toxin Weapons Convention: Countering the Threat from Biological Weapons* (Cmd 5484) (London: TSO). (At <http://www.fco.gov.uk/Files/kfile/btwc290402.pdf>)

Rappert, B (2003), 'Biological Weapons, genetics and social analysis: emerging responses, emerging issues – I', *New Genetics and Society* Vol.22 No.2 pp.159-181. (Part two in the following number is worth reading too).

Rappert, B and McLeish, C (2007) (eds), *Web of Prevention: Biological Weapons, Life Sciences and the Governance of Research* (London: Earthscan, 2007) (esp chapter by Atlas)

Durodie, B (2004), 'Facing the Possibility of Bioterrorism', *Current Opinion in Biotechnology* 15: 264-268.

Dando M (1994), *Biological Warfare in the 21st Century* (London: Brassey's) (Chapter 4) (A very readable introduction on the nature of BW) (See also chapters 1,8,10)

Tucker JB (1994), 'Dilemmas of a Dual-Use Technology: Toxins in Medicine and Warfare', *Politics and the Life Sciences* Vol.13 No.1 pp51-62. (Wellcome Library)

Useful web sites:

Peace Studies, University of Bradford (lots of introductory information and analysis – including videos!): <http://www.brad.ac.uk/acad/sbtwc/>

Stockholm International Peace Research Institute: www.sipri.se/

Harvard Sussex Program on CBW Armament and Arms Limitation:

www.sussex.ac.uk/spru/hsp/

The Program also publishes *The CBW Conventions Bulletin* with news, background and commentary. Back issues available on the web: <http://www.fas.harvard.edu/~hsp/bulletin/>

Federation of American Scientists (Has initiative on CBW arms control): www.fas.org/

Topic 9 Human Experimentation

This topic covers human experimentation from a sociological and policy perspective. Although we will touch on the ethics of human experimentation, we will be more concerned with what motivates people to take part in biomedical research, what (if any) contribution they can make if they are given a 'voice' rather than being treated as passive research material, and how we theorise the researcher-subject relationship.

Essential Reading:

EITHER

Steven Epstein (1995) 'The Construction of Lay Expertise: AIDS Activism and the Forging of Credibility in the Reform of Clinical Trials' *Science, Technology & Human Values*, Vol. 20, No. 4, 408-437

OR

Goodare,H., & Lockwood,S. (1999). Involving patients in clinical research. *British Medical Journal* 319 724-725.

OR

Williamson,C. (2001). What does involving consumers in research mean? *Quarterly Journal of Medicine* 94(12), 661-664. [for a consumer perspective]

Additional Reading

See also <http://www.ucl.ac.uk/researchvolunteersforum/>

This website, established in 2011, has an online information resource with readings and brief commentary

Gripping yarns [Books you can dip into – sensational and thoughtful stories about human experimentation. Make a selection]

Goodman,J., McElliot,A., & Marks,L. (2003). *Useful bodies: humans in the service of medical science in the twentieth century*. Baltimore: Johns Hopkins University Press

Lederer,S.E. (1995). *Subjected to science: human experimentation in America before the second world war*. Baltimore: Johns Hopkins University Press.

Moreno,J. (2001). *Undue risk: secret state experiments on humans*. London: Routledge

Oakley, A (2000). Chapter 11 of *Experiments in knowing: gender and method in the social sciences*, Polity Press, Cambridge.

Governance of research on humans [Useful background; get the gist]

DoH/Department of Health (2001). *Research Governance framework for health and social care*. London: Department of Health

Nuremberg Code (1949). [find this and others on the web or reprinted in: Vanderpool, H.Y. (1996). *The ethics of research involving human subjects*. Frederick, MD: University Pub. Group].

World Medical Association (2002). *Declaration of Helsinki*. Washington DC: World Medical Association.

Fisher, J A (2007) 'Governing human subjects research in the USA: individualized ethics and structural inequalities', *Science and Public Policy*, 3 (2) pp 117-126.

Active patients and research subjects

Rabeharisoa, V and Callon, M, 2004. 'Patients and scientists in French muscular dystrophy research'. In Jasanoff, S (ed) *States of Knowledge: the co-production of science and social order*, London, Routledge.

Weinstein, M. (2001). 'A public culture for guinea pigs: US human research subjects after the Tuskegee study'. *Science as Culture* 10(2), 195-223. [fascinating insight into 'professional guinea pigs']

Epstein, S (2008), 'Patient Groups and Health Movements' in Hackett, EJ *et al* (eds) *The Handbook of Science and Technology Studies*, Third Edition (Cambridge: MIT Press).

Epstein, S. (1996). *Impure science: AIDS, activism and the politics of knowledge*. Berkeley: University of California Press.

Volunteers' understandings

Corrigan, O. (2003). Empty ethics: the problem with informed consent. *Sociology of Health and Illness* 25(3), 768-792.

Featherstone, K., & Donovan, J. (2002). "Why don't they just tell me straight, why allocate it?" The struggle to make sense of participating in a randomised controlled trial'. *Social Science and Medicine* 55 709-719.

Morris, N. and Balmer, B. (2006). Volunteer human subjects' understandings of their participation in a biomedical research experiment. *Social Science & Medicine*, 62(4), 998-1008

Researcher-subject relationships

Corrigan, O and Tutton, R (2006). 'What's in a name? Subjects, volunteers, participants and activists in clinical research'. *Clinical Ethics*, 1, 101-104.

Morris, N. and Balmer, B. (2006). Are you sitting comfortably? Perspectives of the researchers and the researched on 'being comfortable' *Accountability in Research*, 13, 111-133.

Motivation / Social perspectives

Ross, S., Grant, A., Counsell, C., Gillespie, W., Russell, I., & Prescott, R. (1999). Barriers to participation in randomised controlled trials: a systematic review. *Clinical Epidemiology* 52(12), 1143-1156.

Titmuss, R.M. (1971). *The gift relationship: from human blood to social policy*. London: LSE Books.

ALSO RELEVANT: papers by Rabeharisoa and Callon, and by Weinstein, listed earlier.

Topic 10. Animal Experimentation

Most of the literature on animal experimentation focuses on ethics – is it right or wrong. While not wholly ignoring this debate, a more policy-orientated social science literature tries to understand the social dynamics of the debate. From this perspective analysis tries to understand how the debate gets fought; what sort of rhetoric, strategies or tactics are employed on both sides; why people become involved in the issue etc.

The Wellcome Information Service (see front of reading list) has a large collection of material on issues in animal experimentation and you are encouraged to explore their resources.

The social dynamics of the debate:

These are not arguments for or against, but analyses of the history of the issue and of the types and styles of arguments used:

Essential Reading

Sanders, S and Jasper, JM (1994), 'Civil Politics in the Animal Rights Conflict: God Terms versus Casuistry in Cambridge, Massachusetts', *Science, Technology and Human Values* Vol.19 No.2 pp169-188

Additional Reading:

Michael M and Birke L (1994), 'Accounting for Animal Experiments: Identity and Disreputable "Others" ', *Science, Technology and Human Values* Vol.19 No.2 pp189-204

Nelkin D and Jasper JM (1992), 'The Animal Rights Controversy', in Nelkin D (1992), *Controversy: The Politics of Technical Decisions* (3rd Edition) (Newbury Park: Sage) pp26-44. [[Available on-line from library: click Online <http://ls-tlss.ucl.ac.uk/> and search for this course, tick the 'previous year' box to make sure]

Pivetti, M (2007), 'Natural and unnatural: activists' representations of animal biotechnology', *New Genetics and Society* Vol.26(2): 137-157.

Frickel, S et al (2010), 'Undone Science: Charting Social Movement and Civil Society Challenges to Research Agenda Setting', *Science, Technology and Human Values* 35(4):444-473. [See CASE STUDY No.4.]

Holmberg, T and Ideland, M (2012), 'Secrets and lies: "selective openness" in the apparatus of animal experimentation', *Public Understanding of Science* vol. 21 no. 3: 354-368

Jasper, JM and Poulsen, J (1995), 'Recruiting Strangers and Friends: Moral Shocks and Social Networks in Animal Rights and Anti-nuclear Protest', *Social Problems* 42(4):493-512 (Looks at recruitment to protest movements via 'moral shocks' of visual and verbal rhetoric).

Jasper, JM and Poulsen, J (1993), 'Fighting Back: Vulnerabilities, Blunders, and Countermobilization by the Targets in Three Animal Rights Campaigns', *Sociological Forum* Vol.8 (4): 639-57.

McAllister Groves, J (1997), *Hearts and Minds: The Controversy Over Laboratory Animals* (Temple: Philadelphia) (Esp. Intro, Chs 5-6 and conclusion). [Wellcome]

Munro, L (2005), 'Strategies, Action Repertoires and DIY Activism in the Animal Rights Movement', *Social Movement Studies* Vol 4 (1): 75 – 94. (Argues, based on empirical study, that the majority of animal activists employ non-violent means).

Web-Sites:

The Research Defence Society: <http://www.rds-online.org.uk/>

People for the Ethical Treatment of Animals: <http://www.peta-online.org>

Royal Society for Prevention of Cruelty to Animals: <http://www.rspca.org.uk/>

ESSAY TOPICS FOR POLICY ISSUES
IN THE LIFE SCIENCES
Autumn 2012-13

Assignments 1 and 3: Essay

Assessed work should not be more than 10% longer than the prescribed word count. Word count excludes your bibliography but does include footnotes.

Essay 1: Focussed Essay

This essay should be approximately 1,500 words long and focus on the main issues in order to answer the question set (i.e. don't write a general essay on the subject). As a rough guideline, I would expect you to draw on the essential reading(s) for the topic plus about 3-4 other sources.

Essay 2: *Detailed separately later*

Essay 3: Longer Essay

This essay should be approximately 2,500 words long and you are expected to read widely around the topic. You do not need to use all your sources to the same extent in order to answer the question set (i.e. don't write a general essay on the subject), but you do need to demonstrate that you have consulted a range of relevant sources.

Format

Essays should be spell-checked, 1.5 line spaced, minimum 12 point type with citations to references both in the essay and with a list of these references at the end. You must include **page numbers** and a **word count** (that excludes bibliography). I prefer Harvard referencing style (Google it) but you can use any citation convention as long as you are consistent, consult some of the journals on the reading list for styles.

Please read the guidelines on how to write an essay or consult: **A. Northedge (1990), *The Good Study Guide***. Students who wish to write an essay connected with the course but not on the list should see me to discuss a title. See the front of your reading list for due dates.

You can do an essay on a topic that we have not covered yet; this will be taken into consideration during marking

Essay 1 and 3 Questions:

1. Should scientists be left to themselves to decide on priorities and goals for biomedical research?
2. Researchers interviewed by Lock claimed that "it is paternalistic not to hand out information to patients [about genetic test results] already known to science" (Lock 2011, p699). Lock disagrees. Who do you agree with and why?
[You can add a further question: "Is it ever appropriate to withhold the results of a genetic test?"]

3. Forensic experts have claimed ‘Physical evidence speaks for itself. It doesn’t lie, it has no bias, it doesn’t forget and it doesn’t change’ (quoted in Robert & Dufrense 2008). So, what – if anything - is problematic about DNA profiling in the criminal justice system?
4. How, if at all, does the concept of ‘framing’ help us understand the GM crop debate? Can it help resolve the debate?
5. The BSE crisis is often regarded as a turning point in the relationship between science and politics. Why was it seen in this light and what were the key lessons to draw from the episode? [NB. You do not need to give a complete history of the crisis in your essay]
6. Is the Biological Weapons Convention an outdated relic of the Cold War?
7. Outline the main social and ethical issues raised by the emergence of synthetic biology? Which issues, if any, are of most concern (explain your justification)?
8. Participants in biomedical research are usually treated as ‘research subjects’. What difference, if any, does it make to involve ‘consumers’ (patients/volunteers) in biomedical research as more than simply ‘subjects’?
9. Briefly outline the strategies and tactics employed by advocates and opponents of animal experimentation. Can studies of the social dynamics of the debate contribute to its resolution?

Assignment 2: Review

This assignment should be a brief (900 word) review of *one* item¹ from the reading list which should be taken from a topic on the course for which you do not write an essay.

Your review should concentrate on one item, but also read 2-3 other items to place the review in context.

You should use the following as a check list. Not all of the points will be relevant or necessary for every review.

- Clearly set out the title(s) of the piece(s) you are reviewing. You should also give your review a title.
- Provide the reader with an outline of the contents of the pieces(s), including:

What question(s) is (are) being asked by the author(s)? What problems are being addressed? What are the main arguments or claims being made? What evidence is used to support this argument? *If relevant:* what research methods and theoretical perspectives have been used?

However - do not spend too much of your word quota on this descriptive material.

¹ An item from the reading list would be (a) a journal article (b) all assigned chapters from a single authored book or (c) a single chapter from an edited book collection (a) a book. Avoid purely technical pieces. Do not review short news items or commentaries that are less than two pages (if in doubt ask BB before starting your review).

- Your review should also be analytical:

What are the strengths and weaknesses of the argument(s)?

What are the strengths and weaknesses of the authors' use of evidence?

If relevant: what are the strengths and weaknesses of the research methods and theoretical perspectives used?

Note: It is essential that you don't just provide a judgement but also the reasons for your judgement e.g. don't just say that 'the argument is strong', 'the section on X is good' say why it is strong or what is good about it

- While the clarity of the writing is important and can be commented on, this is not the main point of your review which should focus on the substantive content of the piece reviewed.
- What is the context of the review – i.e. how does this item fit in with the topic in general (this is why it is important to do two or three other readings for context).
- If reviewing more than one chapter/article: How do the articles relate to each other?
- Final points - e.g. ask yourself: What use has the book or article(s) been for me (and why)? Are there any remaining questions to be cleared up? Finish with an *overall* judgement about the articles or book.
- The journals *Public Understanding of Science*; *Social Studies of Science*; *Science, Technology & Human Values* and *Minerva* have reviews, covering individual books and also longer essay reviews, which may be worth using as models.
- Three examples of high scoring assignments from previous years are on the Moodle site.